



A Professional Care Coordinator's Guide to Partnering with Family Caregivers

Care coordination is usually considered a professional role and responsibility. Professional care coordinators – nurses, social workers, and administrative staff – bring many skills and resources to this job. That said, it is often assumed but not explicitly recognized in a care plan that family caregivers also will play an important role in care coordination.

This guide (and its companion guide for family caregivers) suggests ways for you as a professional care coordinator to partner with family caregivers and to prepare them for taking on additional coordination responsibilities when your services end.

The Role of Professional Care Coordinators

There is no standard definition of what constitutes care coordination, who should be doing it, and how its effectiveness should be measured. For example, the federal Agency for Healthcare Quality and Research (AHRQ) found over 40 different definitions, depending on setting, provider, goal of the program, and other factors. Despite their differences, all the definitions share some common elements:

- Care coordination is systematic and organized
- Care coordination is team work involving several people, including the patient
- Care coordination requires communication among all participants

Few of the definitions explicitly recognize the role of the family caregiver in coordinating care, even though care coordination is a major activity for family caregivers. In a national survey family members taking care of someone with complex medical needs – those most in need of care coordination – were more than twice as likely to be the primary care coordinator as those who provided only ADL or IADL assistance. The vast majority of all caregivers in the survey who were doing care coordination were doing it alone: only 3 percent reported having a care coordinator from a government program or insurance plan, or a private care manager.¹

In general, care coordination involves scheduling and arranging the services and supplies needed to maintain the health and well-being of a seriously or chronically ill person. These can be related to the person's medical care, or to the ability to live at home, or to participate in community activities. Essential to the professional care coordinator's role are:

- Building rapport with the patient and family,

¹ S. Reinhard, C. Levine, S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care*. Washington and New York: 2012, p. 16. Available at <http://www.uhnyc.org/publications/880853>.

- Explaining how the system works,
- Explaining the boundaries of scope and length of involvement (since most professional care coordination is time-limited),
- Ensuring that the patient, caregiver, and health care providers (including other professional care coordinators) are working from the same understanding of the patient's needs and the plan of care, and
- Preparing the patient and family caregiver to take on additional care coordination duties when your services end.

If there is any concern about the patient's or family caregiver's ability or willingness to follow the care plan, or to participate in care coordination, the professional care coordinator is responsible for reporting back to the clinical team or other appropriate service provider.

The Role of Family Caregivers in Care Coordination

As a professional care coordinator, you have a set of priorities for your work on behalf of patients and their families. You have relationships with care providers, easy or automatic methods of communication (electronic records, secure email, etc.), and the ability to schedule and authorize or request authorization for specific services. Family caregivers are often left with everything else – the parts of care coordination that are outside your role or expertise, that depend on family caregiver follow up, or that you simply did not know was a need. Here are four examples:

- You may work hard to set up an appointment for a consultation with a specialist, but the family caregiver has to coordinate all the steps it takes to get the person ready for the visit, arrange transportation, and take time off from work to accompany the patient. Any misstep in this chain of events can mean a missed appointment and a potentially worsening medical condition.
- The family caregiver is struggling with financial problems and doesn't know where to turn. This is outside your area of expertise but keeping the person at home depends on finding some additional support.
- You have ordered durable medical equipment for the person and it has been delivered. But the family caregiver doesn't know how to assemble or operate it and puts it away rather than letting you know about the problem. The caregiver is hesitant, possibly even afraid, to reveal this lack of understanding.
- Your new patient is a 71- year- old grandmother with a heart condition who is responsible for the care of her 25-year-old grandson with developmental disabilities. To accommodate the new limitations on the grandmother's ability to provide care, you will need to work with his service coordinator to find other resources.

There are other factors that affect family caregivers' interactions with care coordinators. **There may be multiple professional care coordinators involved in the person's care** – from health insurance, from MLTC (managed long-term care), from the hospital, and from a community-based service agency. **The family caregiver may be confused about which professional care coordinator is**

responsible for which aspect of the care plan and will have to learn how to coordinate the coordinators.

This is often a time of reorganization for the family; family member roles may shift and new stressors may arise that may take a toll on the family system. While your job is to coordinate services, a family caregiver's job is to coordinate life, and your help can make that job much easier.

Remember that **there may be more than one family member involved in the person's care**. Find out who is responsible for what aspects of care coordination, such as medication management, so that you speak to the right person about the specific aspect of care.

What Professional Care Coordinators Can Do to Build Partnerships

Three strengths of professional care coordinators are:

1. An understanding of how the health care system works in general and how to access services;
2. A systematic, organized approach to identifying care needs and coordinating the appropriate services; and
3. Access to technology that can facilitate sharing information, bringing team members together, and communicating regularly.

Family caregivers can benefit from your knowledge and insight. In turn, family caregivers can assist you in doing your job through their intimate knowledge of the person and what interventions have succeeded (or failed) over time.

To harness these strengths, **there are specific activities that professional care coordinators can do during each encounter:**

- **Invest in the Beginning²**
 - **Talk with patients and listen carefully to their own goals for care.** Patients rarely state these in clinical terms like lowering their blood pressure but frequently refer to being able to walk to a store, participating in a future family event, or resuming a leisure activity.
 - **Talk with family caregivers and listen carefully for their own goals for the patient's care.** Family caregiver goals may be very different from patient goals; family caregivers may be focused on going back to work, getting uninterrupted sleep, or attending to children's needs. Ask about other care coordination or caregiving responsibilities; these may impact the family caregiver's abilities or availability and should be accounted for in the care plan.
 - **Pay close attention for verbal and nonverbal cues that the person may be upset, confused, or overwhelmed.** Follow up on cues, even if you suspect that

² R Frankel, T Stein, E Krupat. The Four Habits Approach to Effective Clinical Communication. *Clinician-Patient Communication* series, The Permanente Medical Group (2003).

you may not be able to address the underlying issues. Often, acknowledging a problem (even if it cannot be “fixed”) is comforting and helpful.

- **Elicit the Patient’s (and Caregiver’s) Perspective**
 - With their goals in mind, **help patients and families identify what needs to be arranged immediately and what can wait.**
 - **Work with family caregivers to identify the level and types of care that are realistic for them to do.** Be open to differences in what each family caregiver is willing and able to do – remember that family caregivers may (and sometimes should) say “no” (which may mean that additional services must be found), and that sometimes family caregivers need training on that task before they can say “yes.” The *Next Step in Care* guided assessment tool may be helpful (http://www.nextstepincare.org/Provider_Home/What_Do_I_Need/).
 - **Stay task-oriented when making plans.** This gives clear direction to your actions and the family caregiver’s, and in listening, you may gain helpful insights into the caregiver’s understanding of the patient’s situation.
 - **Think broadly about what services patients and family caregivers need,** even if they are not within your organization’s program.
 - **Ask family caregivers how they are doing, and what their own needs are.**
- **Demonstrate Empathy**
 - **Avoid jargon.** Health care professionals often use industry terms and acronyms (“ADLs” or “skilled care”). Take care to use non-health care, conversational language.
 - **Use professional interpreter services for all communication with people whose primary language is not the same as your own.** Family members, especially young children, and friends who are bilingual are **not** appropriate translators. While they may have good intentions, family and friends may paraphrase or adjust information, either out of concern and respect for the patient, or from misunderstanding.
 - **Respect cultural differences about family decision making, care at home, and use of outside services.** Make no assumptions based on ethnicity, religion, or family structure: ask how decisions are made in the family, and to whom you should speak about various services and arrangements.
- **Invest in the End**
 - **Build confidence in family caregivers’ abilities to manage care.** Allow them the opportunity to express their fears and doubts.
 - **Clarify mutual expectations.** Be very specific about what you will do and what the family caregiver has agreed to do in terms of making appointments, notifying of cancellations, or other tasks. Caregivers have many responsibilities, and after the discussion may be uncertain about who is doing which task.
 - **Provide realistic avenues for support.** Handing a caregiver a number to call is not a referral; calling the number together and facilitating the caregiver’s efforts to

connect with services is more effective. Learn about community resources and the best ways to refer patients and families to them. See the *Next Step in Care* guide on referring caregivers to community-based services

(http://www.nextstepincare.org/Provider_Home/Community_Based_Services/).

- **Create realistic expectations about access to services and length of time services such as home care may be available.** For example, family caregivers may assume that an aide will come to the home every day, although insurance will only cover a few days per week.
- **Acknowledge when you do not have all the answers** and will have to do some further research. Report to the family caregiver what you find out as quickly as possible.
- **Follow through on promises** to find resources or make arrangements. The job isn't done until you've closed the loop with the person and family caregiver.

Care coordination is a team effort. Make sure that the family caregiver is an integral part of your team.

Additional Resources

For more information on professional care coordination, please see the Safety Net Medical Home Initiative's Implementation Guide on care coordination

(<http://www.safetynetmedicalhome.org/sites/default/files/Implementation-Guide-Care-Coordination.pdf>) and AHRQ (<http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/index.html>).

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